

Activity and participation after spinal cord injury: State-of-the-art report

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Abstract—The importance of activities and community participation for persons with spinal cord injury (SCI) has been recognized for decades and yet theoretical and empirical advances have been limited. This report summarizes the recommendations for researchers on the topic of measuring activity and participation among persons with SCI formulated by the Spinal Cord Injury workgroup at the State-of-the-Art Conference on Outcome Measures in Rehabilitation held in January 2010. Activity and participation were defined as independent constructs ideally measured in reference to personal values and environmental influences. Measures of activity, participation, and factors influencing activity and participation are reviewed and critiqued. Gaps in available measures are described, measures in development are discussed, and suggestions for future research are made.

Key words: activity, disability, employment, functioning, measurement, outcomes, participation, quality of life, rehabilitation, spinal cord injury.

Abbreviations: 10MWT = 10 m walk test; ADL = activity of daily living; ASSIST = Alcohol Smoking and Substance Involvement Screening Test; AUDIT = Alcohol Use Disorders Identification Test; BBS = Berg Balance Scale; BDI = Beck Depression Inventory; BMCA = brain motor control assessment; CAT = computerized adaptive testing; CCI = Charlson Comorbidity Index; CDE = common data element; CES-D = Centers for Epidemiologic Studies-Depression scale; CHART = Craig Handicap Assessment and Reporting Technique; CHIEF = Craig Hospital Inventory of Environmental Factors; CPI = Community Participation Indicators; DSM = Diagnostic and Statistical Manual of Mental Disorders; DSM-IV = DSM-Fourth Edition; EMG = electromyogram; FABS/M = Facilitators and Barriers Survey/Mobility; FIM = Functional Independence Measure; ICF = International Classification of Functioning, Disability, and Health; IPA = Impact on Participation and Autonomy; IRT = item response theory; ISNCSCI = International Standards for the Neurological Classification of Spinal Cord Injury; LIFE-H = Assessment of Life Habits; LiSat = Life Satisfaction Questionnaire; NIDRR = National Institute on Disability and Rehabilitation Research; NINDS = National Institute on Neurological Disorders and Stroke; NIH = National Institutes of Health; PARA-SCI = Physical Activity Recall Assessment for People with Spinal Cord Injury;

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Abbreviations: (cont.) PARTS/M = Participation Survey/Mobility; PHQ-9 = Patient Health Questionnaire-9; PRO = patient-rated outcome; PROMIS = Patient-Reported Outcomes Measurement Information System; QOL = quality of life; RR&D = Rehabilitation Research and Development; SCI = spinal cord injury; SCI/D = spinal cord injuries and disorders; SCI-FAI = spinal cord injury Functional Ambulation Inventory; SCIM = Spinal Cord Independence Measure; SCSC = Spinal Cord Injury and Disorders system of care; SOTA = State-of-the-Art; VA = Department of Veterans Affairs; WHO = World Health Organization; WISCI-II = Walking Index for Spinal Cord Injury-II; WST = Wheelchair Skills Test; WWII = World War II.

INTRODUCTION

Prior to World War II (WWII), persons who sustained a spinal cord injury (SCI) could expect to survive only weeks, and even if the odds of survival had been in their favor, no rehabilitative care was available that would have allowed them to pursue ordinary life aims [1]. Owing to advances in emergency medicine, antibiotics, and other aspects of acute medical care, thousands of veterans who sustained an SCI in the conflicts of WWII were able to return home. The survival of these individuals prompted the Department of Veterans Affairs (VA) to develop the first specialized care centers dedicated to SCI in the United States, broadening the aims of care for persons with disabilities to include comprehensive restoration of their functional potential in physical, social, vocational, emotional, and recreational areas of life [2]. By the closing years of WWII, three dedicated SCI care centers were opened by the VA. Today, the VA Spinal Cord Injury and Disorders system of care (SCSC) has expanded to 24 SCI care centers that administer specialized care to approximately 17,000 veterans with spinal cord injuries and disorders (SCI/D), making the VA the largest single provider of SCI/D care in the world [3]. In contemporary times, the lifespan of a veteran with SCI/D can be measured in decades. As a result, the attention of clinicians, researchers, and veterans with SCI/D is increasingly turned toward understanding and optimizing psychosocial functioning, such as activity levels and community participation.

Veterans with SCI/D comprise a distinct population deserving additional attention in research and clinical settings for several reasons. The average age of veterans

with SCI/D is 55 years, approximately 18 years older than that of their counterparts in the SCI Model Systems. Little is understood about outcomes among older persons with SCI/D. Nearly half of all veterans with SCI/D served by the VA have injuries of nontraumatic etiology; little empirical literature characterizes the psychosocial concerns of persons with nontraumatic SCI/D. Veterans also tend to have lower socioeconomic status and more comorbid medical conditions than the general population, suggesting they may be at increased risk for lower levels of functioning.

As lifespans lengthen among veterans with SCI/D, there is increasing awareness of issues related to aging with SCI/D and a growing need to focus resources on understanding how to assess and address lapses in activity levels and community participation in this population. VA SCSC is extensive and comprehensive and has been in development for more than 65 years, and yet, there is only a limited body of empirical knowledge about veterans with SCI/D that could inform care providers or veterans about important outcomes. Most of what we know about SCI/D comes from research that does not involve veterans, and little of that research has involved populations that are even comparable to veterans on demographic and medical factors (e.g., older age, non-traumatic injuries). As just noted, veterans with SCI/D are different from other populations in important ways, and whether research involving nonveterans with SCI/D will generalize is unknown.

A clear need exists for empirical research aimed at gaining a better understanding of activities, participation, and other outcomes among veterans with SCI/D. Future research among veterans with SCI/D could benefit from a synthesis of expert opinion on the measurement of activities and participation and recommendations for research. Against this general background, this report describes findings of the SCI Workgroup from the State-of-the-Art (SOTA) Conference on Outcome Measures in Rehabilitation, sponsored by the VA Rehabilitation Research and Development (RR&D) Service.

SPINAL CORD INJURY WORKGROUP METHODS

A group of researchers and clinicians in the field of SCI rehabilitation was selected by the SOTA organizers and invited to participate in a 2-day workgroup. Participants were selected based on their expertise in SCI

research and clinical care and to represent numerous SCI rehabilitation disciplines and diverse VA and SCI Model Systems sites. A diverse panel of participants was selected so that recommendations for instruments and research would be prepared with real-world use and implementation in mind. Workgroup participants were given the charge to draw upon their knowledge base and expert opinion to formulate recommendations for researchers on the topic of measuring activity and participation outcomes among persons with SCI. To formulate recommendations, the workgroup held evaluative discussions of instruments that are currently being used or developed to measure outcomes after SCI. Measures were evaluated according to the volume and quality of published empirical support for measures and workgroup members' opinions on the practical utility of measures in clinical settings. During and after the SOTA meeting, several of the committee members performed limited literature reviews to supplement the results of the workgroup discussions and to better place workgroup recommendations within the context of past empirical and theoretical work. Importantly, the objective of the SOTA was not to conduct a comprehensive review of the research literature on these topics. Rather, the aim was to develop and share commentary and recommendations from the standpoint of expert opinion. Workgroup members held two telephone conferences subsequent to the SOTA to review and refine findings.

OVERVIEW OF RECENT LITERATURE ON ACTIVITY AND PARTICIPATION AFTER SPINAL CORD INJURY

In the last decade, interest has surged in the conceptualization and measurement of activity and participation among rehabilitation populations. The timing of this SOTA was fortuitous because participants were able to refer to recent empirical publications and consensus statements when formulating final recommendations. What follows is an overview of recently published reports germane to the measurement of activity, participation, and similar constructs among persons with SCI.

In November 2001, a National Institute on Disability and Rehabilitation Research (NIDRR)-funded conference convened to discuss the state of the science of measuring quality of life (QOL) in rehabilitation medicine [4–5]. QOL was described as the emphasis of an out-

comes model for evaluating rehabilitation care in the resulting series of articles [6]. Tate et al. reviewed the literature on QOL after SCI [7]. They noted that popular measures of QOL have limited utility among persons with SCI because of inappropriate questions for persons with locomotor disabilities and insensitivity to personal values or interpretations of QOL. Similar concerns were reviewed in depth by Hays et al. in the same series [8] and by other investigators in more recent years [9–10]. With those limitations in mind, past research has shown that persons with SCI evidence lower QOL than persons without SCI and that their QOL may decline with age. QOL among persons with SCI has consistently been associated with various conceptualizations of participation, such as involvement in the community, employment, marriage, and social support [11]. QOL has not shown consistent or strong associations with biomedical factors such as etiology or severity of injury [11].

In 2007, NIDRR supported a symposium to clarify the state of knowledge about postacute rehabilitation outcomes, identify research challenges, and promote research [12]. In a publication reporting from the symposium, Clohan et al. noted that activity and participation measures are inadequately developed, especially in areas such as emotional well-being, vocational involvement, and family systems [13]. Duncan and Velozo suggested the use of item response theory (IRT) and computerized adaptive testing (CAT) to develop measures of rehabilitation outcomes [14]. The symposium recommended that SCI researchers (1) develop cognitive and psychosocial outcome measures that are low in respondent burden and valid across populations using IRT and CAT; (2) develop participation, activity, and social support measures; (3) evaluate reliability and validity of measures; and (4) assess environmental factors to allow adjustment of outcomes.

In 2008, NIDRR sponsored a broad review of outcome measures in SCI research, including a participation workgroup [15]. The workgroup reviewed the empirical literature to identify participation measures appropriate for use among persons with SCI. Three measures met criteria of having been used with people with SCI, cited in literature between 2000 and 2007, and used by two or more research groups. The three measures that met these criteria were the Craig Handicap Assessment and Reporting Technique (CHART) [16], the Assessment of Life Habits (LIFE-H) [17], and the Impact on Participation and Autonomy (IPA) questionnaire [18] (**Table 1**). However, the authors noted that existing measures are inadequate for

Table 1.

Social and emotional measures.

Domain/Measure	Acronym	Description	Limitations	Population
Social				
Craig Handicap Assessment and Reporting Technique	CHART	32-item questionnaire scored in domains physical independence, cognitive independence, mobility, occupation, social integration, and economic self-sufficiency.	Excludes subjective appraisals. Ceiling effects.	SCI
Assessment of Life Habits	LIFE-H	77- to 240-item measure of activities and participation providing 12 subscales: nutrition, fitness, personal care, communication, housing, mobility, responsibility, interpersonal, community, education, employment, and recreation.	Emphasizes motor activity.	Any
Impact on Participation and Autonomy	IPA	32-item questionnaire assessing participation and restrictions. Subscales include social relations, self-care, mobility, leisure, family role, work, and education.	Floor and ceiling effects. Smaller evidence base.	Persons with disability
Life Satisfaction Questionnaire	LiSat	9-item measure of life satisfaction in domains global, vocational, financial, leisure, friends, sexual, activities of daily living, family life, and partnership.	Limited SCI research.	Any
Emotional				
Beck Depression Inventory	BDI	21-item measure of depressive symptoms.	Lengthy and does not match DSM-IV criteria.	Any
Centers for Epidemiologic Studies-Depression	CES-D	20-item measure of depressive symptoms.	Lengthy and does not match DSM-IV criteria.	Any
WHO Alcohol, Smoking and Substance Involvement Screening Test	WHO ASSIST	8-item measure screening for lifetime and current other drug use, dependence, and impairment.	—	Any
Patient Health Questionnaire-9	PHQ-9	9-item measure matching DSM-IV criteria for major depression.	Somatic symptoms overlap with SCI issues.	Any
Alcohol Use Disorders Identification Test	AUDIT	10-item measure of alcohol misuse, symptoms of dependence.	—	Any

DSM-IV = Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition, SCI = spinal cord injury, WHO = World Health Organization.

addressing the person-environment interaction inherent to participation and that some measures give no consideration to personal values. They recommended that future measures address these conceptual limitations and be developed utilizing modern measurement techniques.

Noonan et al. compared the psychometric performance of three measures of participation and found ceiling effects for each measure [19]. Otherwise, psychometric performance was adequate for all measures. Post et al. reviewed measures of participation that have been utilized among persons with SCI in published

research [20]. Measures were reviewed for psychometric evidence and coverage of the International Classification of Functioning, Disability, and Health (ICF) [21] domains of activity and participation, with the Life Satisfaction Questionnaire (LiSat) [22] being recommended as the superior tool (**Table 1**).

The above efforts are complimentary on a number of points. First, each considers activity and participation critical outcomes among persons with SCI. Furthermore, appropriate measures for persons with SCI are lacking, primarily because of measures containing content that is

a poor fit for someone who does not mobilize by walking or a lack of empirical study of the measures among persons with SCI. Those measures that have been utilized among persons with SCI often show limitations such as ceiling effects or weak and inconsistent associations with other relevant constructs. Finally, activity and participation are highly individualized constructs and it may be necessary to assess or account for influential environmental factors. In fact, participation is defined by interaction with environmental factors in some quarters.

Clearly, activity and participation are important but conceptually complex constructs, and this could well account for inadequacies in empirical research in this area. Whiteneck and Dijkers recently described conceptual and methodological issues with the construct of participation and environmental factors that interact with impairment [23]. The authors note that participation and environmental factors that interact with impairment are inadequately conceptualized in the ICF [21] and that lack of theoretical clarity impedes successful measurement. Whereas the ICF suggests multiple methods for classifying activity and participation, the authors take the stance that participation and activity should be conceptualized and measured as distinct constructs. The authors suggest a number of conceptual distinctions between activity and participation. Activity is considered action by an individual that can be assessed as a characteristic of a person. Participation may involve numerous activities that occur with or for others to fulfill societal roles. Participation is assessed at the level of person and environment.

SCI workgroup recommendations were informed by the theoretical and empirical efforts just reviewed. In the interest of formulating recommendations for research on activity and participation among veterans with SCI, the SCI workgroup adopted the following objectives:

1. Define constructs of activity and participation after SCI.
2. Recommend measures of activity and participation after SCI.
3. Describe gaps in available measures of activity and participation after SCI.
4. Identify factors that influence activity and participation after SCI.
5. Recommend measures of factors that influence activity and participation after SCI.
6. Describe gaps in measures of factors that influence activity and participation after SCI.
7. Recommend directions for future research.

CONCEPTUALIZING AND MEASURING ACTIVITY AND PARTICIPATION AFTER SPINAL CORD INJURY

For the purposes of this SOTA, “activity” was understood to refer to the broad class of behavioral, cognitive, and emotional experiences of individuals. “Participation,” by contrast, was considered to refer to persons’ interactions with their social environment. The drawing of this conceptual distinction between activity and participation is considered one option for utilization of ICF classifications [21] and is consistent with other expressed theoretical positions [23]. The workgroup also considered the measurement of factors that influence activity and participation to be critical in discussions of activity and participation measurement. After all, physical barriers, attitudinal bias, mental health problems, and medical problems can influence what a person with mobility impairments is able to do. These considerations are especially relevant to veterans with SCI/D because past research has suggested that the general veteran population may be more at risk for medical problems and psychosocial dysfunction than nonveterans [24–26]. With the aim of inclusively identifying factors with potential influence on activity and participation, the workgroup organized influential factors within social, emotional, physical, medical, and environmental domains.

EXISTING MEASURES OF ACTIVITY, PARTICIPATION, AND INFLUENTIAL FACTORS

Activity Measures

Available activity measures are diverse, ranging from reports of activities of daily living (ADLs) to objective measures of motor activity (**Table 2**). In the next sections, ADL and motor activity measures are discussed separately.

Activities of Daily Living Measures

The Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI) was developed specifically for persons with SCI in order to objectively measure the type, frequency, duration, and intensity of specific physical activities [27]. The PARA-SCI is an interview tool organized around recall of activities undertaken during the 3 previous days, yielding scores for cumulative activity, leisure-time activity, and lifestyle

Table 2.

Physical measures.

Measure	Acronym	Description	Limitations	Population
Physical Activity Recall Assessment of People with Spinal Cord Injury	PARA-SCI	Interview tool about activities in the 3 previous days, yielding activity scores for cumulative, leisure time, and lifestyle.	Limited evidence base. Emphasis on physical activity.	SCI
Spinal Cord Independence Measure	SCIM	19-item measure of functioning after SCI with 3 scales: self-care, respiration and sphincter management, and mobility.	—	SCI
Functional Independence Measure	FIM	18-item scale quantifies activity limitations by assessing performance in self-care, sphincter control, transfers, locomotion, communication, and social cognition.	Nonspecificity for SCI. Not sensitive to neurological status.	Any
GAITRite	GAITRite	Device recording special and temporal gait parameters.	No application in nonambulatory.	—
SMARTwheel	SMARTwheel	Measures force and torque applied to wheelchair handrim.	—	Wheelchair users
10 m Walk Test	10MWT	Assesses short-distance walking speed as index of walking capacity.	No application in nonambulatory.	Any
Brain Motor Control Assessment	BMCA	EMG-based assessment of motor control.	—	Any
Walking Index for Spinal Cord Injury-II	WISCI-II	Measure of walking ability based on use of assistance from persons and devices.	No application in nonambulatory.	SCI
The Spinal Cord Injury Functional Ambulation Inventory	SCI-FAI	Rater-scored measure of walking ability.	No application in nonambulatory.	SCI
Wheelchair Skills Test	WST	Measures 50 wheelchair skills in 10 functional categories.	—	SCI
Berg Balance Scale	BBS	14-item test of balance.	No research in SCI.	Any

EMG = electromyography, SCI = spinal cord injury.

activity. The reliability and validity of the tool have been demonstrated by the developers in recent years [27–29]. Limitations of the PARA-SCI include limited use by investigators beyond the developers, emphasis on physical activity, exclusion of subjective appraisals, and the technical complexity of interview administration.

The Spinal Cord Independence Measure (SCIM) is a disability scale developed for patients with SCI [30]. The SCIM measures the following areas of function: self-care, respiration and sphincter management, and mobility. Each area is scored according to its proportional weight in general activity. The final score ranges from 0 to 100 and rates functional achievements according to their importance [30]. The SCIM shows high interrater reliability and has been found to be more sensitive to changes in function than the Functional Independence

Measure (FIM) [30]. In the SCIM II, some SCIM items were rephrased to improve reliability of the scale [31]. A third version of the SCIM (SCIM III), made up of three subscales, was formulated following comments by experts from several countries and Rasch analysis performed on the SCIM II. The results supported the compatibility of the SCIM subscales with the stringent Rasch requirements. The scores of each SCIM III subscale appear to be reliable and useful quantitative representations of specific constructs of independence after SCI. The results also suggest that there is merit in further refining the scale [32].

The FIM is probably the most widely used functional assessment measure in clinical rehabilitation and research [33]. This 18-item scale quantifies activity limitation by assessing performance in self-care, sphincter

control, transfers, locomotion, communication, and social cognition on a 7-point ordinal scale (1 = complete dependence, 7 = complete independence). If the points for each item are added, the possible total FIM score ranges from 18 to 126.

The psychometric properties of the FIM have been studied extensively and shown to be reliable [34]. In a Rasch analysis of the FIM, two separate domains were defined: motor and cognitive [35]. Research has shown that the cognitive domain is not informative for persons with SCI because of a substantial ceiling effect and limited sensitivity to change over time [36]. Other limitations of the FIM include (1) nonspecificity for SCI; (2) inability to detect subtle, but important, difference in functional levels between paraplegia and tetraplegia [37]; and (3) less applicability to outpatient rehabilitation settings.

Motor Activity Measures

A number of objective measures of motor activity and mobility are available. The GAITRite system (CIR Systems, Inc; Havertown, Pennsylvania) was designed to be a simple tool for use in clinical and research settings for assessment of gait. This device is able to record spatial and temporal gait parameters as a person walks over an electronic walkway. Three-dimensional motion capture systems have been used to demonstrate validity and test-retest reliability [38–39]. These outcome measures can be used to quantitatively assess changes in a person's gait due to an intervention such as robotic locomotor therapy and resistance training in SCI.

The SMARTwheel was developed as a method for measuring the force and torque applied to the handrim of a wheelchair [40]. The measure is considered to be informative for optimizing propulsion techniques and selecting wheelchairs [41–42].

The 10 m walk test (10MWT) was initially developed to assess short-distance walking speed [43–45]. The 10MWT is a validated, reliable measure for assessing walking function and capacity in individuals with SCI [45–46]. The 10MWT is responsive to initial rehabilitation and ongoing improvement in locomotor capacity in those with incomplete SCI [47]. A limitation to the 10MWT is that its reliability can be influenced by a patient's poor walking function that may be due to reasons other than walking ability [48].

The brain motor control assessment (BMCA) provides a quantitative method to characterize motor control in persons with neurological disorders. This is done by

using multichannel surface electromyogram (EMG) recordings and protocols to evaluate control of neck, shoulder, trunk, upper-limb, and lower-limb muscles in the supine position. These recording are compared with patterns recorded from neurologically intact control subjects. BMCA has been used to demonstrate the ability to modify EMG reflex excitability in many persons clinically classified as complete SCI [49]. Applications include documentation of treatment effects for returning motor control [50], assessment of spasticity and cocontraction [51], and provision of objective criteria for the selection of intervention strategies [52].

The Walking Index for Spinal Cord Injury-II (WISCI-II) was created to measure ability to walk after an SCI. It is a validated and reliable ranking tool for use in SCI population clinical trials. The assessment index is completed by ranking a person's ability to walk on a scale from 0 (most impairment) to 20 (least impairment). The ranking is based on an individual's use of physical assistance from one or more persons, braces, and other devices. The WISCI-II ranking is based only on the severity of impairment and cannot be used as an indicator of functional independence [53–54]. A study found that the WISCI-II is sensitive to recovery of walking ability [55].

The Spinal Cord Injury Functional Ambulation Inventory (SCI-FAI) is a rater-scored measure of walking ability in persons with SCI [56]. The SCI-FAI has moderate to good interrater and intrarater reliability. SCI-FAI scores showed a 45 percent improvement after a training program. Overall, this assessment tool appears to be good for persons who can ambulate, but has no application for non-weight-bearing individuals with little to no walking ability [56].

The Berg Balance Scale (BBS) is a validated and reliable 14-item scale initially developed to measure balance in the elderly [57–58]. Another validated use of the BBS is predicting falls within the elderly population [59]. The materials needed to complete the test include two chairs (one with arms and one without), a ruler, a 6-inch step, and a stopwatch. The measure is primarily used in the clinical setting and takes 15 to 20 minutes to administer [60]. The BBS has recently been studied for use as a balance tool [61] in the SCI population. A limitation of the BBS is that it has not been validated for use in individuals with SCI at this time.

Assistive technology for mobility, including wheelchairs, plays an important role in community participation among persons with SCI. For example, a recent

study found that individuals with SCI perceived wheelchairs as the most significant factor limiting participation, beyond the impact of neurological impairment [62]. Wheelchair-related mobility can be measured by several methods, including direct observation and recording of distance and speed, activity questionnaires, heart rate monitoring, and calorimetry for estimating energy expenditure [63]. A number of factors can be associated with level of wheelchair mobility. Among them, wheelchair skills are currently under investigation by the SCI Model Systems researchers. The Wheelchair Skills Test (WST) is a measure that objectively evaluates wheelchair skills required for daily functioning. The WST version 2.4 measures 50 skills in 10 areas that are scored on a 2-point scale (0 = fail, 1 = pass) to produce four summary scores: total score, total percentage, left/right asymmetry ratio, and goal attainment score. This instrument has been tested among persons with SCI, showing acceptable reliability and validity [64].

Participation Measures

Four measures of participation were considered by the workgroup to have sufficient levels of evidence to justify use among persons with SCI (Table 1). Characteristics and limitations of each measure are now reviewed.

The CHART tool can be considered the most widely used participation instrument among persons with SCI [16]. The CHART is a 32-item measure that yields scores in domains including physical independence, cognitive independence, mobility, occupation, social integration, and economic self-sufficiency. Validity and reliability of the CHART have been demonstrated in studies of persons with SCI [16,65]. The CHART was specifically designed to focus on objective criteria rather than subjective interpretations of participation, such as life satisfaction. Therefore, one important limitation of the CHART is its conceptual exclusion of subjective appraisals of participation. Also, the CHART has significant ceiling effects; more than half of samples of persons with SCI attain maximum scores on most CHART subscales [65]. Consequently, its use for characterizing higher levels of participation is limited and its skewed distribution will impact statistical analyses.

The LIFE-H measures both accomplishment and satisfaction with daily activities and social roles [17]. Conceptually, it is a measure of activities and participation. It is a lengthy instrument, consisting of 77 (short form) or 240 items (long form) that are derived to provide 12 par-

ticipation subscales: nutrition, fitness, personal care, communication, housing, mobility, responsibility, interpersonal relations, community, education, employment, and recreation. The measure has demonstrated adequate psychometric qualities [66], including evaluations using IRT and Rasch modeling [67]. The length of the LIFE-H may represent significant burden to respondents and administrators. While the LIFE-H does have a body of published studies demonstrating its strengths, this work was largely done by the developers of the instrument. Many of the “life habits” appraised in the LIFE-H items emphasize motor activity, so the measure has been criticized as being potentially biased against persons with greater motor impairment [15,66].

The IPA is a 32-item measure designed to assess perceived participation and participation restrictions from the point of view of persons with disability [18]. It includes subscales of social relations, autonomy in self-care, mobility and leisure, family role, and work and educational opportunities. Studies have supported its reliability, validity, and factor structure among persons with SCI [18,68–70]. Limitations of the IPA include some floor and ceiling effects and relatively less use empirically than other activity and participation measures [15,71].

The LiSat is a 9-item self-report scale measuring life satisfaction [22]. Conceptually, the instrument can be considered to measure satisfaction with participation [36]. In the LiSat, one global item assesses “life as a whole” while the eight remaining items each addresses satisfaction with a different life domain: vocational situation, financial situation, leisure, friends, sexual life, ADLs, family life, and partnership relationship. The measure was developed for use among the general population, but in recent years it has been in seven published studies of persons with SCI [69]. In these studies, its reliability and factor structure have been supported [72]. Data supporting the measure’s validity among persons with SCI are more limited [72].

Measures of Influential Factors

Psychological Domain

In the domain of psychological functioning, depression and substance abuse stand out as common comorbid conditions that negatively affect participation after SCI [73–74]. With regard to depression, numerous measures have been studied and no single measure seems preminent.

Therefore, we selected five widely used measures to comment upon.

The Beck Depression Inventory (BDI) is the most frequently used measure of depression in SCI, with at least 44 studies on people with SCI published but only 2 with psychometric data [75]. The 21 items are scored on a 0–3 scale that is unique to each question. The traditional cutoff score for clinically significant depression is 10 or more. However, a validity study comparing the BDI with a Diagnostic and Statistical Manual of Mental Disorders (DSM)-Third Edition-Revised structured clinical interview for depression found that a cutoff of 18 or more resulted in optimal sensitivity (83%) and specificity (91%) in people with SCI [76]. Advantages of the BDI are its widespread use and comparison samples, sensitivity to change, and relevance to cognitive-behavioral therapy treatment approaches. Disadvantages are the overall length, lack of parallelism with DSM-Fourth Edition (DSM-IV) nosology, and inclusion of somatic symptoms that may be caused by SCI. The BDI II published in 1996 is shorter and matches DSM-IV symptoms and time frame [77].

The Centers for Epidemiologic Studies-Depression scale (CES-D) is a 20-item scale designed to measure depressive symptoms in the general population [78]. Items are scored on a 4-point Likert scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time) during the past week. The CES-D has been used in at least 37 studies, including 12 with psychometric data and 2 that focused specifically on validity [73]. The CES-D appears unidimensional. The standard cutoff score for determining significant depressive symptoms is 16 or more. However, in a Thai sample, a cutoff of 19 or more resulted in a sensitivity of 80 percent and a specificity of 70 percent compared with a diagnosis of major depression based on psychiatric interview [73]. An advantage of the CES-D is its acceptability and de-emphasis on somatic symptoms. Disadvantages are length and lack of comparability to DSM-IV criteria.

The Patient Health Questionnaire-9 (PHQ-9) is a 9-item screening measure constructed to exactly parallel the DSM-IV criteria for major depression [79]. Items are coded on a 0–3 scale from not at all to nearly every day during the past 2 weeks. A total score of 10 or more had the best combination of sensitivity (88%) and specificity (88%) when compared with a depression diagnosis in primary care [79]. Responses can be scored according to DSM-IV symptom criteria to increase the specificity of the measure and reduce

false positives [79]. The PHQ-9 has been used in at least seven studies of people with SCI, including two designed to measure psychometric properties. No studies have evaluated the diagnostic validity of the PHQ-9 compared with a diagnostic interview for major depression in people with SCI. Advantages of this measure are its brevity, parallelism with DSM-IV criteria, and inclusion of a suicidal ideation item. A limitation of the PHQ-9 is the inclusion of somatic symptoms that may be attributable to SCI or the hospital environment. As with other measures, the likely etiology of somatic symptoms should be considered carefully, especially if the PHQ-9 is used in acute care or inpatient rehabilitation [80].

Substance abuse is also a common comorbid condition in people with SCI. Substance abuse measures may cover consumption, symptoms of dependence, and substance use-related problems or impairment. The Alcohol Use Disorders Identification Test (AUDIT) consists of 10 items covering all 3 domains in a very brief format [81]. The AUDIT has been used in at least one published study of SCI [82]. Using a cutoff of eight or more, the sensitivity and specificity of the AUDIT in detecting alcohol dependence in primary care are 74 and 89 percent, respectively [83]. The three AUDIT consumption questions alone (referred to as the AUDIT-C) are almost as accurate in detecting alcohol dependence as the AUDIT [83].

The World Health Organization (WHO) developed the Alcohol Smoking and Substance Involvement Screening Test (WHO ASSIST) as a screen for lifetime and current (past 3 months) drug use, dependence, and impairment [84]. The WHO ASSIST consists of 8 items covering 10 substances. It is a reliable and valid indicator of drug use and dependence compared with a structured diagnostic interview. No published studies have used the WHO ASSIST in people with SCI. Advantages of the WHO ASSIST over other drug abuse screening measures are its coverage of tobacco, alcohol, and other drugs all in a brief format; the availability of the measure in multiple languages; the strong validity data; and its ability to discriminate low, moderate, and high risk substance use for any substance.

Medical Domain

Medical complications occur with unfortunate consistency after SCI, with a strong impact on functioning, so measurement of medical comorbidities is recommended as a part of an assessment of activity and participation. Two

measures were discussed by the SCI workgroup as being of possible utility to investigators (**Table 3**).

The Charlson Comorbidity Index (CCI) identifies and weighs important comorbid conditions that were originally identified as predictors of mortality in a general medical population [85]. With this index, medically diagnosed conditions have preset point values such that those of more severe morbidity risk (e.g., metastatic tumor) are assigned a point value of 6 while less severe ones (e.g., peripheral vascular disease) are assigned 1 point. Patients are assigned weighted points for each condition. The sum total is stratified according to severity (none to mildly ill, moderately ill, severely ill). The weighted index was developed using 1-year survival and tested for its ability to predict 10-year survival [85]. The CCI is not well studied among persons with SCI, and it does not serve as an index of comorbid conditions common after SCI, such as urinary tract infection, pressure ulcers, or spasticity.

The Duke Severity of Illness is a clinician-rated instrument for measuring illness severity or burden. The clinician selects up to three of a patient's most serious illnesses and provides ratings of symptom level, complications, prognosis without treatment, and treatability. Limitations include a modest level of reliability [86] and no validation in persons with physical disability.

Environmental Domain

Theoretical models of activity and participation recognize the importance of environmental influence.

Within the domain of environmental factors, however, instrument development research has been limited. Rienhardt and Post recently reviewed measures of environmental influences on participation in SCI [87]. Six measures were identified that had been used in SCI populations and had been published with psychometric data. Of those measures reviewed, the Craig Hospital Inventory of Environmental Factors (CHIEF) [88] was described as having superior psychometric performance (**Table 3**). The CHIEF consists of 25 items that assess the frequency and magnitude of perceived social, attitudinal, policy, and physical/architectural barriers that keep people from doing what they want or need to do. A total score ranging from 0 to 8 is derived, with higher scores indicating great frequency and/or magnitude of environmental barriers. The CHIEF has been tested in persons with SCI and achieved acceptable reliability [88]. CHIEF scores also seem to be associated with the type and severity of the disability. The CHIEF Short Form is a 12-item version of the CHIEF that includes those items with the greatest conceptual clarity and discriminant validity. In a study of 2,726 persons with SCI who registered in the SCI Model Systems database, Whiteneck et al. reported that the CHIEF Short Form subscales accounted for only 4 percent or less of the variation in participation [88], which may reflect the limitations of CHIEF, including (1) assessment of barriers but not facilitators, (2) subjective perception rather than more objective criteria, and (3) dichotomization of the scale.

Table 3.

Medical and environmental measures.

Domain/Measure	Acronym	Description	Limitations	Population
Medical				
Charleson Comorbidity Index	CCI	Index of general medical comorbidities used to calculate total score reflecting risk for mortality.	Does not include SCI-specific comorbidities.	Any
Duke Severity of Illness	DUSOI	Clinician-rated instrument for measuring illness severity or burden.	Modest level of reliability. No validation in persons with SCI.	Any
Environmental				
Craig Hospital Inventory of Environmental Factors	CHIEF	25-item measure assessing frequency and magnitude of perceived social, attitudinal, policy, and physical/architectural barriers to participation.	No facilitator assessment. Subjective criteria. Dichotomization of the scale.	Any

SCI = spinal cord injury.

GAPS IN MEASURES OF ACTIVITY, PARTICIPATION, AND INFLUENTIAL FACTORS

Recent research has provided various measures of activity, participation, and influential factors that are adequate for use among persons with SCI. However, investigators should be aware of the limitations of these measures to inform selection and use and to direct future research on measurement development.

A leading concern among available measures is that persons with SCI are not included in the development or psychometric study of the measures. This can contribute to the inclusion of items that are inappropriate for persons that mobilize primarily via wheelchair or to an overemphasis on culturally normative definitions of activity and participation. Similarly, responses to some items in depression measures may be influenced by ordinary somatic experiences of persons with SCI. The ceiling and floor effects noted among a number of measures could also be a result of an absence of persons with SCI in development samples and conceptualizations of activities and participation that are based on the values and experiences of nondisabled persons. Very little is known about the sensitivity to change of measures of activity and participation among persons with SCI.

The SCI workgroup noted an absence of measures of certain important outcomes and influential factors. First, measures tend to focus on deficits and pathology to the exclusion of positive experiences and high functional performance. This tendency is manifested in ceiling effects and selection of pathological constructs, e.g., depression. As compared with activity and participation, relatively few measures of environmental factors are available; perhaps this reflects the complexities inherent in defining and measuring environmental factors. Standardized methods for quantifying healthcare delivery and benefit systems are needed to facilitate understanding of how these factors influence outcomes and for allowing cross-system and international comparisons.

MEASURES IN DEVELOPMENT

In addition to all the measures that are being used, several future measurement instruments are currently under development, in the process of validation, or nearing the point of published findings that have significant potential to be superior to some older measures (**Table 4**).

These measures may eventually replace several of the existing measures. They should continue to undergo further consideration for common data elements (CDEs) as evidence of sound psychometric characteristics, normative data, utility in SCI research, and presence in the literature evolve. These future measures will fill some of the existing gaps in measurement of SCI-related sequelae and may employ more sophisticated validation techniques than older measures. Additionally, some of these measures may better facilitate comparison across patient groups (e.g., different disease populations, broader age range). In many respects, future measures are considered by the workgroup to have the potential to be superior to existing measures.

The workgroup acknowledges that the selection of recommended outcome measures is a flexible and dynamic process that will undergo further evolution in the coming years as additional evidence emerges and as testing of these measures as CDEs is undertaken. All the measures listed here have been selected as the best measures at the time of this publication; nevertheless, the workgroup advises that the reader consult the literature for updates to this listing as measures undergo further development and testing.

The Participation Survey/Mobility (PARTS/M) is a survey designed for persons with mobility impairments and based on the ICF definition of participation [89]. Published research on the PARTS/M has been limited beyond the initial study of its statistical properties. The Community Participation Indicators (CPI) [15] is an instrument in development that will integrate objective and subjective definitions of participation. The CPI is currently being pilot tested.

Two measurement systems that have great potential to become leading instruments are the SCI-QOL and SCI-CAT. These are based off of the Patient-Reported Outcomes Measurement Information System (PROMIS) [90] and Neuro-QOL [91] systems being developed by the National Institutes of Health (NIH).

The PROMIS is a new measurement system that was developed as part of NIH Roadmap to improve the clinical research enterprise [92]. The PROMIS Network has developed and tested a large bank of items measuring patient-reported outcomes over several domains, including physical functioning, sleep disturbance, fatigue, anxiety, depression, anger, social roles, and social activities [93–94]. Item banks have been calibrated, allowing tests to be administered as a CAT or as short forms to ensure

Table 4.

Measures in development.

Measure	Acronym	Description	Limitations	Population
Community Participation Indicators	CPI	Measure integrating objective and subjective definitions of participation.	Limited body of research.	Any
Facilitators and Barriers Survey/Mobility	FABS/M	133-item measure of personal and community facilitators and barriers to participation.	Limited body of research.	Mobility impairments
Community Health Environment Checklist	CHEC	63-item measure of physical barriers to participation in environment.	Limited body of research.	Mobility impairments
Participation Survey/Mobility	PARTS/M	Measure of community participation.	Limited body of research; length.	Mobility impairments
Spinal Cord Injury Quality of Life	SCI-QOL	PRO measure covering multiple domains of functioning: depression, grief, resilience, anxiety, positive psychological, stigma, self-esteem, role performance, role satisfaction, independence, bowel, bladder, respiratory, pain, skin breakdown, sexual, and satisfaction with sexual functioning.	Limited body of research.	SCI
Spinal Cord Injury Computerized Adaptive Testing	SCI-CAT	PRO measure assessing multiple domains of functioning: mobility, wheelchair mobility, walking, upper limb, and communication.	Limited body of research.	SCI
Autonomic Nervous System Standards	ABS Standards	Developed to augment neurological classification to document impact of SCI on autonomic function.	Measure is in development.	SCI

PRO = patient-rated outcome, SCI = spinal cord injury.

the assessment is brief. The measure is designed as a generic measure to be used across all medical populations.

The Neuro-QOL is also a patient-rated outcome (PRO) measurement system funded through a contract method by the National Institute on Neurological Disorders and Stroke (NINDS) [95]. The Neuro-QOL team has developed separate item banks covering the following domains: mobility/ambulation, ADL/upper limb, depression, anxiety, positive psychological functioning, stigma, perceived and applied cognition (includes communication), social role performance, social role satisfaction, fatigue, personality and behavioral change, and sleep disturbances. Embedded in several of the Neuro-QOL domains are a significant number of PROMIS items and attempts will be made to link the PROMIS and Neuro-QOL measures. The Neuro-QOL is designed to provide PROs for clinical trials research sponsored by the NINDS.

The SCI-QOL is a new multifaceted PRO measure of functioning under development that is cofunded by the National Institute of Child Health and Human Development/National Center for Medical Rehabilitation Research and the NINDS that embeds Neuro-QOL and PROMIS items. Separate item banks are being developed to measure bowel maintenance/functioning, bladder maintenance, bladder complications, pain, skin breakdown, depression, grief/loss, resilience, anxiety, positive psychological functioning, stigma, social role performance, social role satisfaction, independence/autonomy, sexual functioning, and satisfaction with sexual functioning [96]. The SCI-QOL calibration item banks include all the relevant Neuro-QOL items along with several PROMIS items to provide linkages between these systems with the goal of creating equivalency score, allowing individuals who complete the SCI-QOL to also receive a Neuro-QOL

score and a PROMIS equivalency score. Because the SCI-QOL and SCI-CAT systems have been developed with the input of individuals with SCI, these measures should expand upon the Neuro-QOL and PROMIS measurement systems with items and item banks that expand the specificity of the instrument. A collaborative team involving the University of Michigan, Kessler Foundation/Kessler Institute for Rehabilitation, Rehabilitation Institute of Chicago, Craig Hospital, University of Washington, Northwestern University, and the James J. Peters VA participated in the large field testing of the items involving more than 900 individuals with traumatic SCI. Calibrated item banks are being developed and validation studies examining responsiveness to change, convergent and discriminant validity, and test-retest reliability will be conducted as two validation studies. A grant from the VA RR&D has been awarded to the James J. Peters VA to validate the SCI-QOL in VA-based samples.

The SCI-CAT is a new, multifaceted PRO measure to assess activity limitation/functional activities in individuals with SCI and was funded by the NIDRR as part of the Spinal Cord Injury Model Systems Program [97]. Like the measurement systems just discussed, the SCI-CAT has embedded items from the Neuro-QOL and PROMIS physical functioning, mobility, and upper-limb item banks with the potential of linking scores between the measures. The SCI-CAT includes calibrated item banks for basic mobility, wheelchair mobility, ambulation, self-care, and fine motor functioning. Six model systems centers (University of Michigan, Boston University, Kessler Foundation/Kessler Institute for Rehabilitation, Rehabilitation Institute of Chicago, Craig Hospital, and Mount Sinai Medical Center) have participated in the development of the SCI-CAT and field tested the scale in a sample of 855 individuals with traumatic SCI.

In the physical domain, the Thoracic-Lumbar control (Trunk) Scale is currently in development. The Trunk Scale is designed to measure voluntary control of the trunk musculature after SCI [98]. As restorative and regenerative therapies are being developed and accepted clinically, the need has arisen for measures that are more sensitive to the changes in motor control that may result from these interventions. The Trunk Scale is intended to measure motor ability in the thoracic segments (thoracic 2 to lumbar 1), which is not measured by the International Standards for the Neurological Classification of Spinal Cord Injury (ISNCSCI) Impairment Scale [99], significantly reducing sensitivity to change and associa-

tions with function [100]. The Trunk Scale is designed to be sensitive to quality of movement: it distinguishes between functional tasks performed through use of an assistive device(s), orthotic(s), and/or compensatory techniques often taught in traditional SCI rehabilitation versus those tasks/movements performed in a "preinjury" or "noninjured" movement pattern. This sensitivity is one of the key features missing from several existing measures of function, including the FIM and the 10MWT.

Other researchers are working to standardize the measurement of medical complications that can impair participation after SCI. For example, autonomic dysfunction is known to be a common consequence of SCI during both the acute and chronic phases. Autonomic nervous system dysfunction can delay rehabilitation, impair ADL independence and QOL, predispose the person with SCI to developing degenerative pathologies (atherosclerotic heart disease, impaired glucose metabolism, etc.), and may be life threatening (autonomic dysreflexia). The ISNCSCI Impairment Scale was developed to document impairments of motor and sensory function after SCI, but lacks the ability to assess intactness of autonomic function after SCI [99]. The American Spinal Injury Association, the International Spinal Cord Society, and other groups performing SCI research recommend the addition of autonomic standards to the ISNCSCI Impairment Scale to describe the effects of SCI on bowel, bladder, sexual, cardiovascular, broncho-pulmonary, sudomotor, and other autonomic functions. The Autonomic Standards Assessment Form was developed as a new tool meant to augment the ISNCSCI Impairment Scale in order to document the impact of SCI on autonomic function.

Two measures of environmental influence on participation have recently been developed. The Community Health Environment Checklist is a 63-item measure of physical barriers in the environment that can restrict community participation among persons with mobility impairments [101]. The Facilitators and Barriers Survey/Mobility (FABS/M) is a 133-item measure of facilitators and barriers to participation among persons with mobility impairments [102]. The FABS/M assesses barriers and facilitators to participation at the level of individual and community.

FUTURE DIRECTIONS FOR RESEARCH

The SCI workgroup comprised individuals representing SCI Model Systems institutions and VA SCI/D

specialty care centers. This arrangement prompted the reflection that increased collaboration between these organizations could represent an avenue for increasing our understanding of measurement of outcomes after SCI/D, such as activity and participation. The workgroup recommended consideration of methods for greater alignment of outcome measures and outcome measurement studies across VA and Model Systems sites, pursuit of opportunities for interagency funding, and coordination of statistical analyses. In discussing these possibilities, the workgroup acknowledged that the SCI Model Systems sites and the VA have different approaches to healthcare and outcomes and serve dissimilar populations. Interpreting direct comparisons of outcomes between these systems would be difficult; e.g., Would any differences in outcomes be due to population characteristics, systems of care, measurement methods, or multiple factors? Noting those complications, intriguing options for collaborative work remain. For example, large-scale efforts to examine the psychometric performance of outcomes measures could be coordinated. Efforts to provide the field with benchmarks of expected outcomes after SCI/D [103] could be organized across systems.

CONCLUSIONS

Activity and participation represent critical outcomes for persons with SCI/D and yet existing measurement tools in this population have significant limitations. Investigators are encouraged to become aware of the flaws in available measures in order to make informed decisions for specific projects. A number of measures are available that can serve as indices of activity, participation, and influential factors until the next generation of instruments is developed and disseminated.

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